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Men, chronic illness and healthwork: accounts from male partners of women with endometriosis

Nicky Hudson¹ , Caroline Law¹ , Lorraine Culley¹ ,
Helene Mitchell¹ , Elaine Denny² , Wendy Norton¹ 
and Nick Raine-Fenning³

¹Centre for Reproduction Research, De Montfort University, Leicester, UK

²Faculty of Health, Education and Life Sciences, Birmingham City University, Birmingham, UK

³School of Medicine, University of Nottingham, Nottingham, UK

Abstract Currently dominant in medical discourse, the concept of self-management sees the responsibility for health and illness shift from the state to the individual. However, while this emphasis on individual responsibility and management has burgeoned, the role and status of partners and other family members in the management of chronic illness remains under-theorised. While self-management privileges individual responsibility for the management of chronic illness, the role of partners remains unclear. This paper utilises data from a study of heterosexual couples' experiences of living with the chronic gynaecological condition endometriosis to explore how male partners engage in its day-to-day management. In all, 22 couples participated in in-depth, semi-structured interviews with each partner interviewed separately (n = 44). Data were analysed thematically and dyadically, informed by an interpretivist relational approach. The paper utilises the concept of healthwork to describe the illness work, everyday life work, biographical work and emotion work men engaged in. The paper demonstrates how the conceptual value of healthwork is enhanced by incorporating an analysis of the emotional effort required in managing chronic illness. The paper illustrates the value of investigating the role of partners in managing chronic illness to provide a fuller account of the distributed and relational nature of healthwork.

Keywords: gender, intimate relationships, long-term conditions, self-management, care

Introduction

Recent discursive and policy shifts towards the healthy citizen have re-centred the individual as informed, active and responsible for the management of their health (Clarke and Bennett 2012, Jones 2015, Moore *et al.* 2015, Scambler *et al.* 2014, Vassilev *et al.* 2013, Wilson *et al.* 2007). Currently dominant in medical discourse, the concept of self-management sees the responsibility for health and illness shift from the state to the individual (Kendall *et al.* 2011). However, while this emphasis on individual responsibility and management has burgeoned, the role and status of partners and other family members in the management of chronic illness remains under-theorised. A need for greater attention to partners who live alongside those with

chronic illness has been noted, including improved support from healthcare providers (Miller and Timson 2004). This need is particularly pertinent in relation to the additional ‘treatment burden’ that accompanies a redistribution of the labour associated with illness management (May *et al.* 2014).

While studies have interrogated how men *experience* illness (Clarke and Bennett 2012, Courtenay 2000, Nobis *et al.* 2007, O’Brien *et al.* 2007, Reissman 2003, Gough and Robertson 2009), there has been a relative neglect of men *as partners* of those experiencing chronic illness (Hanlon 2012, Ribeiro *et al.* 2007). Greater focus has been placed on women who provide care to male partners, illustrating for example, the impact on women’s experience and expectations of the relationship (Eriksson and Svedlund 2006, Paulson, Norberg, and Söderberg 2003). While a small number of studies do discuss men’s involvement in the management of a partner’s illness, this work largely focusses on older people’s experiences (Eriksson and Sandberg 2008, Ribeiro *et al.* 2007, Sandberg and Eriksson 2007) for example in the context of dementia (Baker and Robertson 2008, Baker *et al.* 2010, Neufeld and Kushner 2009), or in experiences of cancer (Gilbert *et al.* 2014, Maughan *et al.*, 2002, Perz *et al.* 2011). This involvement is commonly conceptualised in terms of care and care-giving (Gilbert *et al.* 2014, Ribeiro *et al.* 2007), which tends to position the associated actions as directed at the person with the condition, rather than seeing the tasks involved as a distributed activity.

While in the last 40 years, ‘care’ has emerged as a policy construct, and an important concept in highlighting the needs and advancing the rights of those who provide care, many people reject the role of ‘carer’ (or indeed ‘cared for’) (Henderson 2001). Terms such as ‘carer’ or ‘caregiver’ have been heavily critiqued because they often imply passivity and dependency, thereby subordinating the care recipient and implying a position of incapacity (Shakespeare 2000). Conceptualisations of caring have tended to ignore the relationship in which care is experienced, treating caring as an activity which is de-contextualised from the reciprocity that forms the basis of many relationships (Henderson 2001). As Molyneux *et al.* (2011) describe, the term ‘carer’ fails ‘as a recognisable and valid description of the relationship between “carers” and those for whom they care. Furthermore, use of the term may imply burden and therefore devalue the individual who is cared for and in this way polarises two individuals who would otherwise work together’ (Molyneux *et al.* 2011: 422).

A closer examination of the day-to-day management of chronic illness, that goes beyond existing conceptualisations of caring and includes a focus on the distributed and relational nature of tasks is therefore of sociological interest. This is especially necessary given that existing studies of caring have tended to neglect the experiences of male partners, and of couples in younger age groups, where the impact of chronic illness on, for example, reproductive decision-making, childcare, and intimate relationships may entail a different set of negotiations. This paper draws on a study of heterosexual couples’ experiences of living with endometriosis, a common chronic gynaecological condition, to explore how male partners engage in its day-to-day management.

Endometriosis is a gynaecological condition with no known cause and with no definitive cure. Prevalence is difficult to estimate, but is generally thought to affect between 2 and 10% of women of reproductive age (Eskanazi and Warner, 1997) and can have a significant impact on women’s quality of life; detrimentally affecting work, social lives and relationships (Culley *et al.* 2013a, Gao *et al.* 2006, Jia *et al.* 2012, Young *et al.* 2015). Its symptoms include chronic pelvic pain, fatigue, painful sex, heavy and painful periods and subfertility. However, it is an enigmatic illness which is often misdiagnosed and takes an average of between 5 and 8.9 years to diagnose (Culley *et al.* 2013a). Women with the condition report experiencing delegitimation of their symptoms by healthcare professionals and others, and uncertainty in terms of its trajectory (Denny 2009). Given the absence of a cure and its uncertain trajectory,

studies demonstrate the considerable burden that day-to-day management of endometriosis brings (Seear 2009). It can also have a negative impact on relationships, and in some cases is reported to have contributed to relationship breakdown (Culley *et al.* 2013a, Jones *et al.* 2004). However, having a partner can also improve quality of life (De Graaff *et al.* 2013) and women report that partners can be an important source of support (Culley *et al.* 2013a, 2013b). There exists a small number of studies on endometriosis that include male partners (Ameratunga *et al.* 2017, Butt and Chesla 2007, Fernandez *et al.* 2006) but most do not explore what partners do on a daily basis or the ways in which partners provide support (Butt and Chesla 2007).

While a multiplicity of concepts are used to describe the tasks and activities associated with managing chronic illness, this paper begins from the perspective that managing chronic illness constitutes *work* or *healthwork*. We draw on Corbin and Strauss' (1985) seminal but under-used paper '*Managing Chronic Illness at Home: Three Lines of Work*', which utilised concepts from the sociology of work to theorise illness experience as a type of work – undertaken by both individuals with chronic illness and their partners. They describe three main lines of work: *illness work* (comprising regimen work, crisis prevention and management, symptom management and diagnosis-related work); *everyday life work* (comprising daily tasks that keep the household going, housekeeping and repairing, occupational work, marital work, childrearing, sentimental work and activities such as eating); and *biographical work*, which are activities 'necessitated by the continual or occasional reconstruction of his or her life' (1985: 230). Using the term healthwork is in keeping with previous work within the sociology of health and illness which recognises that work undertaken to maintain and promote wellbeing and to ameliorate illness is not only undertaken by paid practitioners but also by a range of social actors including those within the family domain (Stacey 1988). Research on endometriosis also demonstrates the considerable healthwork that women undertake and the associated acquisition of expertise and tasks of self-management (Seear 2009, 2014). To avoid the privileging of practical tasks associated with this definition of healthwork, we also draw on theories of emotion work (Hochschild, 1979) to interpret and conceptualise affective aspects related to the management of chronic illness. We use the concepts of illness work, everyday life work, biographical work and add to these the concept of emotion work, to comprise 'healthwork' and to create an organising framework for the paper.

Methods

The aim of the ENDOPART study was to explore the impact of endometriosis on women and their male partners. The main phase of the study involved face-to-face, in-depth, semi-structured interviews with 22 women with endometriosis and their male partners (n = 44). Ethical approval was received from the host university and the East Midlands Leicester NHS Local Research Ethics Committee UK (reference 12/EM/ 0015).

Heterosexual couples were recruited via the national charity Endometriosis UK (n = 11), NHS clinics (n = 5), other support or information groups or organisations – specifically, endometriosis focused online forums and social media support groups, where details of the study were publicised by the researchers and/or other stakeholders (n = 3), and word of mouth, that is, through personal contact with the researchers or other stakeholders (n = 3). Inclusion criteria were as follows: laparoscopic diagnosis of endometriosis; the presence of symptoms for at least a year and partners living together at the time of interview. Because the study sought to explore the impact of endometriosis on partners' shared everyday experiences, and particularly on aspects such as division of labour within the home and the everyday

management of symptoms, it was felt that living together may provide male partners with a more intimate understanding and experience of endometriosis, as something they were 'living alongside'. However, it is recognised that couples living together will be diverse with regard to partners' levels of closeness and mutual involvement with one another. This strategy also excluded couples living apart who may have offered similar and/or different insights into the impact of endometriosis, as well as couples who had decided not to live together because of the strains of the condition.

Sample characteristics

Of the 22 couples who took part, the mean age of the women was 34.8 years (range: 25–50) and the mean age of the men was 36.3 years (range: 26–57). Among the women, 14 were White British, 6 were South Asian, 1 was mixed White/Asian and 1 identified herself as 'White other'¹. Among the men, 13 were White British, 6 were South Asian and 3 identified as coming from 'White other' ethnic backgrounds. At the point of interview, the mean length of relationship was 9.1 years (range: 3–21 years). The mean length of time since onset of symptoms was 13.6 years (range: 2–37 years) and the mean length of time since diagnosis was 4.5 years (range: 1 month–20 years).

Data collection and analysis

Partners were interviewed separately. Interview questions were devised by referring to the literature and in discussion between the team and a specially convened stakeholder advisory group. Interviews were audio-recorded, transcribed verbatim and entered into NVivo to aid analysis. A thematic analysis (Braun and Clarke 2006) was undertaken. One researcher (C.L.) drafted a coding framework, identifying apriori codes from the literature review and interview guide and inductive codes from the full dataset. Five researchers (L.C., N.H., H.M., E.D. and C.L.) then reviewed this framework in relation to a sample of the data (12 interviews) and amendments were made. A sample of data was then coded by two researchers (C.L. and H.M.), using the NVivo coding comparison function to measure inter-coder reliability, following which coding differences were discussed between the two researchers and the coding framework refined as a result. Separately, and following the thematic analysis, the data were also subject to dyadic analysis² to consider the relational aspects of the data in particular (Eisikovits and Koren 2010, Hudson *et al.* 2018). Following the completion of the inductive thematic analysis, the thematic findings were considered deductively in conjunction with existing theories and concepts. The prevalence of men's descriptions of the various forms of support they provided and the 'work' they undertook warranted a consideration of how pre-existing concepts of different types of healthwork (Corbin and Strauss, 1985, Hochschild, 1979) aligned with the data. Codes relating to management of the condition and its impacts as well as intra-relational support (e.g. 'self-management', 'support from male partner to female partner' and 'male partners' role in health care') were extracted and recoded manually by one researcher (C.L.) using the concepts of illness work, everyday life work, biographical work and emotion work as new codes. In the following section, we draw on this analysis to illustrate the range of healthwork tasks undertaken by male partners of women with endometriosis – exploring the ways in which men understand, make sense of and represent these practices. To maintain anonymity within the couple unit (i.e. to prevent participants from identifying quotes from their partner), we have refrained from using descriptive labels, identifiers or pseudonyms (see Hudson *et al.* 2018).

Findings

Illness work

Male partners of women with endometriosis described a range of ways in which they performed illness work, which is defined as comprising regimen work, crisis prevention and management, symptom management and diagnosis-related work (Corbin and Strauss, 1985). The most common forms of illness work the men engaged with were attending healthcare appointments with their partner and engaging in treatment decision-making. It was common for men to attend all or most consultations (post-diagnosis) and they carried out a range of tasks both before consultations – to help women prepare – and during consultations – where they often acted as a second person to provide or take in information.

[Partner] would like write things down . . . So I'd look at what she'd written down [and say] 'do you really want to ask that, do you really need to ask that', sort of thing, you know, 'why? Well, you know, it's a bit early to be thinking about that, focus on that bit and not that bit'. So hopefully I helped her get her questions clear in her head.

While many men felt that ultimately the course of treatment was the woman's decision, they described the roles they played in listening, talking through options and offering opinions. Some saw themselves as offering a valuable, different perspective to aid the process.

We talk about it an awful lot and I like to think that she leans on me to help make the decisions, the larger decisions . . . because it affects me as well, so we kind of function as a unit when we are making decisions.

It was apparent that, on the whole, women were not managing endometriosis alone, but that addressing the condition and its treatment was seen by the men as a shared undertaking, where they played an active and engaged part.

In addition to attending consultations and engaging in treatment decision-making, some men were involved in regimen work, symptom monitoring and management, and the monitoring of treatment efficacy. For example, men described reminding their partners to take painkillers at designated times, ensuring their partner had water and medication at their bedside while they themselves worked night shifts, preparing TENS (transcutaneous electrical nerve stimulation) machines and heat pads for their partner, and also undertaking tasks in post-surgery periods such as helping their partner shower. The distribution of these tasks to male partners, and their active involvement in such tasks, demonstrates the shared nature of healthwork.

Putting the wheat sack in the microwave for a couple of minutes and giving that to her in an evening. Quite often she won't realise that she needs it and then when she does have it, it calms everything down.

When [partner] came out of hospital . . . that was a bit of a giggle trying to shower her, wash her hair for her, because she's really fussy about her hair.

The range and scope of illness work undertaken by men varied considerably. Sometimes it involved mundane activities, at others it involved crisis situations and here men positioned themselves as taking action and problem solving.

A couple of weeks ago, just as she was prescribed the Valium she was up all night crying and I mean proper just crying. . . She was crying all night, all day, and I cancelled all of my appointments that day, we got down to the GP.

A small number of men discussed taking a more authoritative position in relation to their partners' illness, whereby they directed, rather than assisted them in the day-to-day management of life with the condition. In these examples, the men described an approach which went beyond a redistribution of tasks and was more directive in character, whereby they described acting to 'shield' women from negative impacts on their wellbeing:

There were certain things that I was insistent that she didn't do, like bending over things and what have you. I couldn't not let her do anything, because that was the wrong thing to do as well. It was a case of saying, 'look, OK you can do a little bit. You can walk up the stairs.

While not prevalent across the sample, these examples illustrate the variation present in the men's approaches to management. Whatever the approach, the accounts illustrate men's considerable engagement in illness work, which included a range of practices and tasks, and is illustrative of men's desire to actively engage with the burden of endometriosis.

Everyday life work

Everyday life work refers to the daily tasks that keep the household going, housekeeping and repairing, occupational work, marital work, childrearing, sentimental work and activities such as eating (Corbin and Strauss, 1985). As endometriosis put limits on women's abilities and energy to undertake everyday life work tasks, it was common for men to describe taking on additional housework and, in some cases, childcare, on an ongoing basis. Men described doing additional cooking and cleaning to maintain the running of the house, as well as tasks to directly support their partners such as driving them to and from work. Many men were keen to do as much as they could to support their partner and to relieve the burden on them. This was especially pronounced at specific times when she was particularly unwell.

I think I help by helping around the house, coming in and getting dinner ready, washing up, helping with the kids and that's how I feel that I help and getting things done on my rest days when perhaps no-one's around. So it takes the pressure off her that she doesn't feel that she has to do them.

This imbalance in the division of labour was not perceived to be extreme, and therefore its ongoing nature was not described as problematic by men. More difficult were the acute periods of increased everyday life work following their female partner's surgery. While some male partners felt this increased workload was manageable, others described this as excessive and the logistical difficulties resulting from planning and meeting competing demands were evident.

I [would] get up at 5, make sure everything's ready, go off to work, make sure that, you know, there's stuff in the fridge for her to have. Come home, start again, you know, if I was lucky I was sort of getting bed at about eleven and then get up at five again. Particularly for the two weeks, I did admit to her that the two weeks immediately after her last operation, was probably the hardest two weeks of my life, it was just such hard work. (Partner) when she came out was useless, she couldn't do anything for weeks. Then you're like geez, man, the washing pile doubled . . . I cook, I wash, I iron as much as (partner) does, some other things, but just trying to cope with that was immense.

These quotes illustrate the extent to which men perceived their workload, in terms of everyday life tasks, to have increased as a result of endometriosis, and particularly in the periods following surgery – and their perceptions of this workload as physically and logistically demanding. A small number of men alluded to the fact that undertaking everyday life work disrupted the

'natural order', as illustrated by their requiring instructions from their partner and by describing this type of work as 'help' (as emphasised by the authors in bold).

*With the division of housework I try to do as much as I can . . . I am quite **happy to help out** , I will do anything that is **asked of me** . . . I am trying to get her into the habit of asking me to do things. If you want downstairs hovering ask me to do it and I will do it, if you want the washing up done **ask me to do it**.*

*I'm probably just doing a little bit more than I usually did . . . I've just obviously upped it a little bit to try and **help**.*

This talk about everyday life work as 'help' positioned oversight of housework with female partners, keeping the overall responsibility of domestic labour located in the feminine realm. While many men were taking on additional everyday life tasks, there was less evidence of them taking on the *management* of this system of work, leaving women to need to ask their partners to do specific tasks.

Again, a small number of men displayed taking a more authoritative or directive approach to everyday life work. Some men suggested they were well placed, or in some cases 'best' placed, to assess their partner's abilities and limits with regard to housework (i.e. above the woman herself).

At times because she [female partner] is a bit stubborn, in terms of, 'I can do this, I can do that, I want to do this, I want to do that', and not realising when to stop. [I] have to be firm and say, 'look, you're not really well, don't do this, blah, blah, blah. . . you need to rest'.

Biographical work

Corbin and Strauss describe how biographical work is 'necessitated by the continual or occasional reconstruction of one's life' (1985: 230). Disruption to one's expected life trajectory requires reappraisal in the form of biographical work. Building on and responding to the early work of Mike Bury on biographical disruption in the context of chronic illness (1982), Williams (2000) draws our attention to the processes of appraisal or re-examining and revising expectations and plans in response to such disruptions. Endometriosis causes disruption to anticipated life trajectories in a number of ways (see Hudson *et al.* 2016 for a broader discussion). For the male partners in this study, biographical work related particularly to couples' experiences of the impact of endometriosis on sex and intimacy, planning for and having children, and careers and working lives.

Endometriosis can represent a considerable disruption to sex and intimacy for couples, in part, because of the pain women often experience during sex. Men discussed feeling tentative and hesitant with regard to initiating sex, and described having, over time, come to understand the need for a reduction in sexual activity and come to accept this. They described the biographical work that they undertook of assessing and revising the importance of sex within the relationship and replacing existing expectations about sex.

Arguments and the lack of sex would be the worst [aspect of living with endometriosis] but you learn to deal with it, you cope and move on. . .there's a bigger picture, rather than focus on that one thing you have to look at the history and you have to look at the future. . .

Among couples who had sought fertility investigations and/or received treatment (due to endometriosis' potential effect on women's fertility), men described undertaking considerable biographical work to minimise the impact of infertility, or anticipated infertility, on their day-

to-day life and to revise their visions of a life without children, repositioning this as having positive aspects or, at least, as being something they could accept.

I think the fertility has kind of hit me quite hard and I'm kind of trying to come to terms with it. Just trying to put myself in the worst case scenario and just trying to see myself in that situation and think ok if I can't have a family, can't have children then if that's the way it's got to be, that's the way it's got to be.

Endometriosis resulted in several women being unable to work or only working part time. Several men discussed the biographical work they engaged in – in the form of appraisals of their situations and revisions to their everyday life – with regard to their working and financial situations. For example, some men were seeking higher paid employment while other participants described lowering their expectations about spending money on leisure activities. Some men described how the impact on women's employment had impacted on the gender roles in their relationship, resulting in the adoption of more traditional gender roles:

She wants to go out and get a job . . . she wants to earn her own money because at the moment if she wants anything, she has to ask me for money. We have accidentally become a traditional 1950s household, the man goes out to work all day and the little lady is at home!

Alongside this, some men also reported feeling the added pressure of providing a larger share of the household income. Reference to a traditional imaginary of the 'male breadwinner' here is illustrative of the ways in which performances of healthwork may be mediated and shaped by wider social structures and relations. Biographical work, and especially biographical appraisals and revisions, were therefore a significant aspect of a shared experience of chronic illness (see Hudson *et al.* 2016 for an extended discussion of this).

Emotion work

Emotion work constitutes work undertaken to induce or inhibit feelings, either within oneself or within another person, to render them appropriate to the situation; and as referring to the *act* of trying to change an emotion, not the *outcome* of such effort (Hochschild 1979). Emotion work also includes work to display a certain appearance; as 'the management of feeling to create a publicly observable facial and bodily display' (Hochschild 2012: 7). A central component of emotion work is that it may be performed upon others, not only upon oneself, and therefore can involve a two-way, dialogic relationship. However, interrogations of emotion work in the private sphere have usually focused on women's actions (Hochschild 2012). Here we describe the emotion work undertaken by male partners, conceptualising it as a feature of healthwork.

Common within men's accounts were descriptions of emotion work the men were undertaking to inhibit or induce emotions in their female partner. Men described general activity they undertook to demonstrate emotional support to their partner. This included listening and talking things through, comforting and consoling, letting her offload and cry, demonstrating a comforting and caring attitude and reassuring her they would continue to provide support.

I just listen because sometimes I think she just wants to get it off her chest, she just wants to be heard . . . just someone to even hold her hand and just say look it's alright don't worry whatever it is we'll do it together.

Contrasting with dominant portrayals of men as less emotionally engaged, several men in the study described high levels of emotional engagement with their partner, and were keen to offer sympathetic love, care, support and validation.

Another common practice that men reported was the demonstration of optimism and positivity, to both evoke a more positive outlook in their female partner, and to prevent, suppress or halt negative emotions. Men also described working to conceal their own negative thoughts and emotions and to display that the impact of endometriosis on them was minimal or negligible, thereby suppressing their own emotions as mandated by masculine norms.

Yes I am very positive . . . I have always got to be positive for [partner], I am positive myself but I have got to show her I am positive. Because if I can show her I am really excited about this treatment, I am really hopeful for it, that will rub off on her.

All the issues that endometriosis comes with, no sex, no social life, the financial limitations, I take all that in my stride and if I'm not stressed about it then I think it makes a big difference to [partner]. Because if she can see that it's not a worry to me then I know she is concerned about those issues she doesn't worry about it as much. I'll never let her focus on doom or gloom.

A small number of men speculated that the emotion work of displaying positivity and suppressing negative emotions may not be entirely desirable.

Sometimes in the beginning I used to stop her from crying but now if she cries I let her cry because I think it's better to just get it out your system.

Here men often placed themselves as the 'logical' partner in their descriptions of emotion work.

Sometimes when she has been really, really tired and emotional I recognise that as a time when I am needed to almost take the blinkers off and try to get her to see the wider picture and it's not really as bad as she fears.

Women think of everything all at once and guys sort of just say 'don't think of everything just break it down, let's be logical about this, one step at a time'. So I just try to do that really, just try to calm her down, say 'don't think too much, only deal with things that we can deal with'.

These examples demonstrate how men took on responsibility to protect their partner to shield them from both negative emotions and from the impact of stress. Less common, but still apparent, were instances of men performing emotion work upon themselves, in terms of undertaking activities to look after their own emotional wellbeing including taking time away from the relationship to engage with friends or work, using prayer to problem solve and make sense of the experience, employing positive thinking, engaging in denial and distancing themselves from the impacts of the condition on the couple relationship.

When it's really, really bad, it's like for me when it just gets too much, it's just like ok I'm going to have to let you deal with this because I need to protect my own mental health and I need to remove myself from the situation.

Men worked hard to demonstrate emotional support to their partners, to evoke optimism and positivity, and to suppress negativity. One strategy for achieving this was concealing or minimising their own negative emotions. Emotion work was a significant practice associated with the management of chronic illness and took on a range of forms. These data provide a more

holistic account of the affective labour men engaged in when managing life alongside endometriosis and demonstrate the impact that the condition has in this regard.

Variability in and challenges to performing healthwork

While the performance of a range of practices and tasks was a central feature of the men's accounts, there was variance in the extent to which they were performed by individual men. While some were very active and engaged, among others there was little evidence of involvement in the management of their partner's endometriosis, with most men falling in between these two extremes. In addition, the performance of healthwork was problematic for some men and several described barriers to their involvement. Some felt ill-equipped to effectively support their partner – not knowing what to do or say in order to be supportive – and found it hard to know how to comfort or reassure their partner.

I support her in the sense that I understand her condition but other than that there's not really much I can do for her other than take her to her appointments and be with her, just support her and give her hope that everything's going to be alright . . . my partner would probably disagree and say that I haven't been supportive enough but I just don't really know what else I can do.

The symptoms of endometriosis, and side effects from its treatment, can impact on women's emotions making them feel low, depressed and tearful, as well as irritable and angry (Culley *et al.* 2013a). Men described the impacts of these emotions on the relationship dynamics, and found it difficult to persevere with offering support, which they perceived as arising from endometriosis and resulting in relationship tensions.

The strain it puts on your relationship especially when you can see my partner's in pain and you want to help and you're trying to do things and know it's not right because she's in one of those moods. I'm just trying to help you but that can make it even worse. Yes definitely puts a strain on the relationship.

In this way, men appeared to experience limitations to the amount of healthwork they could engage in. Some felt there was simply not enough time available to offer their partner high quality, focussed support (especially where couples had children whose needs also had to be accommodated), and in particular those who had jobs that did not allow for flexible working described limits to their ability to perform healthwork effectively.

Since there is no cure for endometriosis, and treatment is sometimes ineffective, only effective in the short term, and/or causes debilitating side effects, the success of healthwork practices in terms of symptom relief are potentially limited from the outset. This resulted in significant helplessness and frustration for some men. Such challenges may have detrimental effects on men's emotional wellbeing, resulting in feelings of inadequacy.

If you broke your arm I could at least put it in a sling and give you some paracetamols and take you to A&E but for this there's nothing as a man you can [do]... And that is probably the biggest struggle because there is no real outcome is there, the outcome is it's a long process.

At the beginning the biggest issue was you almost kind of feel impotent in your actions because there is nothing you can do to make her better . . . It's that frustration that my partner who I love very dearly is in pain she is suffering and I can't do anything about it, I am sort of stuck what the hell do I do and there is nothing I can do.

The impacts of the condition on male partners and on relationships were multifaceted, and for many these impacts were compounded by strains they experienced in being sufficiently supportive and enacting healthwork to manage the condition and support their partner.

Discussion

Despite its underuse, we argue that the concept of healthwork retains much explanatory value in the context of chronic illness. Conceptualising the management of chronic illness as a form of ‘work’ makes salient, the agency of individuals and the social structures in which they are enmeshed, valorises and aids understanding of the actions undertaken in managing chronic illness, and captures the sense of distributed responsibility associated with such management (Grue 2016, Seear 2009). Significantly, this conceptualisation acknowledges that managing illness is difficult, messy and includes ‘heavy’ work, as well as the considerable burden associated with the ongoing management of life with a long-term condition (May *et al.* 2014). However, interrogations of healthwork, self-management and self-care have largely been applied at the individual level (Vassilev *et al.* 2013). Our data illustrate that men were engaged in a range of practices in support of their partners and that they often found this challenging and onerous. Healthwork allows a nuanced consideration of the distributed and relational nature of illness management, demonstrating that women were not managing endometriosis alone but were doing so in conjunction with multiple and specific activities undertaken by partners.

In addition to its emphasis on practical tasks, we argue for a broader conceptualisation of healthwork, which recognises the reflexive and emotional effort required in managing chronic illness. Our data illustrate that men engaged in emotion work in terms of managing both their own and their partner’s emotional responses to endometriosis. Incorporating emotion work allows for a more comprehensive and holistic understanding of the process of managing illness and a greater understanding of the affective labour that male partners engage in when negotiating the complexities and relational contours of chronic illness and the impacts this may have on their own wellbeing. Such an approach offers a more adequate framing of these management activities in relationships characterised by love and mutual support. We suggest that the healthwork framework – including emotion work – is therefore a valuable and nuanced tool via which to understand the work carried out by significant others and family members, which focuses on the work they do on themselves and their intimate relationships as well as related practical, everyday life work.

Men’s experiences have been insufficiently considered in explorations of the role of partners, family relationships and social networks in the management of chronic illness, and particularly in terms of their roles as partners. A small body of literature has explored men’s accounts of chronic illness, describing men’s attempts to maintain a sense of masculinity in a caring role (Ribeiro *et al.* 2007), the use of discourses of strength and heroic resilience (Gilbert *et al.* 2014), and an emphasis on the importance of self-care for the achievement of control and invulnerability (Clarke and Bennett 2012). These studies interpret men’s responses to self-care and caring activities through the lens of masculinity, illustrating how this informs their approach to the management of chronic illness. While our data resonate with these findings, particularly in relation to men’s use of a managerial approach in some contexts, our data also demonstrate an inclusive, affective approach to illness management, illuminating the complex, varied and contingent character of healthwork within heterosexual relationships. As we show, men were engaged in a diverse range of activities to support and assist their female partners. However, this is not to deny that some practices that men engage in may be problematic for women and this is of particular

significance in the context of endometriosis. Some men described taking a more directive approach to management, describing themselves as bringing a 'logical' perspective or being best placed to make a judgement about the needs of their female partner. Existing research with women shows that they frequently report experiencing delegitimation about their symptoms (i.e. not being taken seriously or being told that they are imagining their symptoms) in a range of contexts, including with healthcare providers (Culley *et al.* 2013a, Young *et al.* 2015). In this context, women are positioned as weak and irrational and self-care seen as activity to rationalise and manage *oneself* (as opposed to simply managing the disease and its symptoms) (Seear 2009, 2014). This includes working upon one's emotional responses and one's rationality, to achieve a valorised form of subjecthood (Seear 2014). Men's attempts to bring a logical or rational perspective to the management of endometriosis may therefore be considered as contributing to a wider set of gendered assumptions about the nature (and even very existence) of endometriosis as a condition, the authenticity of women's experiences and the legitimacy of their response to the condition. Some enactments of healthwork, which are situated in relation to ideas about male rationality, may therefore inadvertently reinforce notions that endometriosis is synonymous with irrationality and that women with endometriosis are inherently irrational.

While no particular patterns or differences were identified between groups of men according to ethnicity with regard to illness work or everyday life work, ethnicity did appear to mediate some men's experiences of biographical work. For example, South Asian participants reported enhanced pressure to have children that necessitated greater engagement with biographical work to address potential and actual infertility (see Culley *et al.* 2013b, Culley *et al.* 2017 and Hudson *et al.* 2016 for a further discussion of these findings). Negotiating reproductive decision-making in the context of chronic illness is currently under-explored in the literature and these findings also contribute to a broader understanding of how chronic illness impacts on such negotiations.

This paper has contributed to a more comprehensive understanding of the relational distribution of healthwork tasks in the context of intimate heterosexual relationships. Investigating the role of partners, and the physical and emotional labour they engage in, is necessary to provide a fuller picture of what constitutes management of chronic illness and its treatment burden across the life course, especially for those in younger age groups where tasks may include caring for younger children. The data demonstrate that partners and family members respond to the expectation and impetus for non-medical management of chronic illness (Ehrlich *et al.* 2018, May *et al.* 2014) and that this may be particularly pronounced in conditions such as endometriosis, where uncertainty and incurability makes non-medical management a central feature of the experience (Seear 2009). However, the performance of these tasks and the level of support given within individual relationships can be diverse and contingent.

More directly considering social networks, family members and existing relationships offers us a way to position the individual within their social worlds and to better take account of, understand and interrogate the ways in which these networks and relationships configure health and illness experiences across the life course (Hudson *et al.* 2016, Kendall *et al.* 2011). These findings illuminate the potential additional support needs this may present for couples living with a long-term condition, since both partners are dealing (in different ways) with the illness and treatment burden. We suggest therefore that more attention be given to the role and needs of family members in existing models and framings of self-management and call for an improved consideration by healthcare organisations and practitioners of the ways in which couples and families can be supported.

Limitations

The study's limitations include a lack of diversity in terms of socioeconomic status, as well as a potential overrepresentation of couples in which the female partner's symptoms were severe, resulting from participant self-selection. Furthermore, the couples were in effect 'survivors' in relationship terms; it may be that these men were engaging in more supportive activity and healthwork than other male partners and as such they may not be representative of male partners of women with endometriosis more generally. The study was limited to heterosexual couples, and an exploration of healthwork in same-sex couples would add additional valuable insights. Finally, all interviewers in the study were female. It is recognised that the interview is a gendered encounter and that this will have had an impact on the interview dynamics. However, the precise implications are impossible to identify and a number of social signifiers can shape interviewer–interviewee relations (Hudson 2012).

Address for correspondence: Nicky Hudson, Centre for Reproduction Research, Edith Murphy Building, De Montfort University, The Gateway, Leicester LE1 9BH, UK. E-mail: nhudson@dmu.ac.uk

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Author Contributions

Nicky Hudson: Conceptualization (equal); Formal analysis (equal); Funding acquisition (equal); Investigation (equal); Methodology (equal); Writing-original draft (lead); Writing-review & editing (lead). **Caroline Law:** Formal analysis (equal); Investigation (equal); Methodology (equal); Project administration (lead); Writing-original draft (equal); Writing-review & editing (equal). **Lorraine Culley:** Conceptualization (lead); Formal analysis (equal); Funding acquisition (lead); Investigation (lead); Methodology (equal); Writing-original draft (equal); Writing-review & editing (equal). **Helene Mitchell:** Conceptualization (equal); Formal analysis (equal); Funding acquisition (equal); Investigation (equal); Methodology (equal); Writing-original draft (equal); Writing-review & editing (equal). **Elaine Denny:** Conceptualization (equal); Formal analysis (equal); Funding acquisition (equal); Investigation (equal); Methodology (equal); Writing-original draft (equal); Writing-review & editing (equal). **Wendy Norton:** Formal analysis (supporting); Writing-original draft (equal); Writing-review & editing (equal). **Nick Raine-Fenning:** Conceptualization (equal); Formal analysis (equal); Funding acquisition (equal); Investigation (equal); Methodology (supporting); Writing-original draft (equal); Writing-review & editing (equal).

Notes

- 1 At the point of the interview, participants were asked to complete a form providing biographical data including their ethnic group. Pre-determined response categories were provided, drawn from Census categorisation.
- 2 The dyadic analysis has not been utilised in this paper, with its focus solely on men's narratives rather than couples' accounts, but further details of this approach can be found in Hudson *et al.* (2018).

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